DOCUMENT RESUME

ED 255 813 CG 018 145

AUTHOR Zweibel, Nancy R.
TITLE Analysis of Family Decision-Making in Selection of Alternatives to Institutionalization: A Tool for Service Planners and Providers.
PUB DATE Nov 84
NOTE 20p.; Paper presented at the Annual Scientific Meeting of the Gerontological Society (37th, San Antonio, TX, November 16-20, 1984).
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Adult Day Care; *Decision Making; *Family Problems; Human Services; Individual Needs; *Information Needs; Models; *Older Adults; Personal Care Homes; *Program Development; *Social Services
IDENTIFIERS Caregivers; *Council for Jewish Elderly

ABSTRACT

Research into the decisionmaking process of families faced with investigating alternatives to institutionalizing frail aged members could yield valuable information for service planners and providers. To analyze the extent to which its original service plan remained responsive to the changing needs of the frail elderly service population, interviews were conduted with 36 family caregivers who contacted the Council for Jewish Elderly (CJE) for planning assistance in selecting alternatives to permanent institutionalization of their frail elderly relatives. Analysis of interview data revealed six alternatives most frequently considered by families: long-term care, companions, supportive congregate housing, counseling, in-home services, and independent housing. Companions and supportive congregate housing services were not provided by CJE. The data on barriers to successful attainment of preferred services indicated that one in four families had sought alternatives which they reported were unavailable, and 35.3 percent reported cost as a barrier to services. Over half of the respondents indicated that some option mentioned by the CJE social worker had been unfamiliar to them. Some respondents reported that their elderly relatives had refused at least one option which the caregiver had considered, and some level of conflict between the caregiver and the elder was present in 61.5 percent of the families. In response to these findings, CJE has begun a planning effort to analyze further how the needs for companion and supportive congregate living characterizing the sample, and the population it represented, could best be addressed. (NRB)

COUNCIL FOR JEWISH ELDERLY

Analysis of Family Decision-Making in Selection of Alternatives to Institutionalization: A Tool for Service Planners and Providers

Nancy R. Zweibel
Research Coordinator

Presented at the 37th Annual Meeting of the Gerontological Society of America, San Antonio, Texas, November 16-20, 1984

INTRODUCTION

As the number of frail elderly in our population has grown, so has the number of families faced with investigating alternatives to institutionalizing frail aged members unable to continue living independently. In weighing their options, these families engage in a decision-making process which is an analog to the planning tasks undertaken by gerontological practitioners as they design new service systems or make improvements upon existing systems of community-based care. Just as planners must establish goals and survey the existing service system before they can identify where their efforts should be directed, so, too, families enumerate their options and select among them in accordance with certain goals they have set for how their relatives' needs should be met.

Research into the decision-making process of families caring for frail elderly members, therefore, has the potential to yield information of significant value for assisting service planners and providers in their efforts to improve the care they offer their aged clients. This paper will briefly describe one such study conducted at the Council for Jewish Elderly (CJE)[1] and how its findings are being put to use to strengthen the continuum of community-based services that are provided by the Agency. The potential of this type of research as a planning tool for other organizations and as a device for clinical investigation will be noted.

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[1]Established in 1972, CJE is a private social service organization which provides a continuum of community-based and institutional services to the elderly in several communities of Chicago.

THE DECISION-MAKING PROCESS AS ANALOG TO SERVICE SYSTEM PLANNING

Diagram 1 presents a schematic representation of the family decision-making process as conceptualized in our study. As the diagram reflects, the need for decision-making is sparked by the development of a problem upsetting the balance which has been reached in care of the elder by the family. This problem is often an acute exacerbation of a chronic situation and is represented in its most surface form by the specific event precipitating the need for assistance (e.g. hospitalization, a wandering incident, a fall, etc.).

In beginning to think about possible solutions for establishing a new equilibrium in the caregiving system, families identify alternatives for addressing their problems. These alternatives may or may not include turning to the formal service system for concrete and/or planning assistance. Each alternative is investigated by the family and during this analytic effort, the advantages and disadvantages of various courses of action are identified.

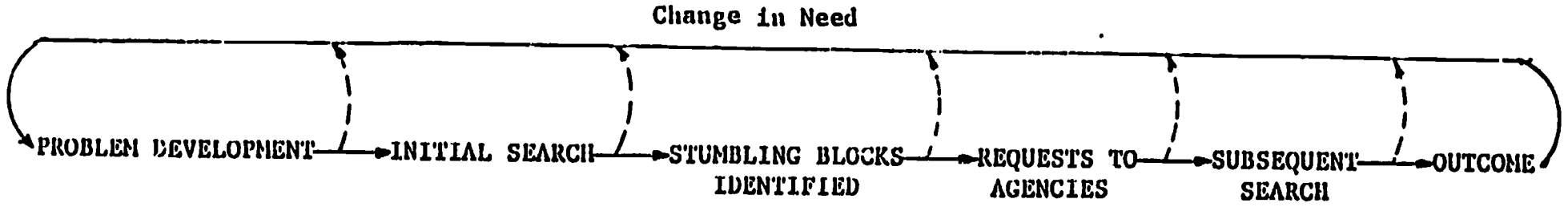
A fundamental assumption of the decision-making model used in this research is that the listing of pros and cons by decision-makers is done through the conscious or unconscious comparison of each existing alternative against some ideal solution. This ideal alternative may or may not be clear to the decision-makers as they analyze their choices, but it nonetheless helps to define the criteria upon which other options are rated and it is the benchmark against which these alternatives are measured.

The investigation of these alternatives results in illumination of stumbling blocks to implementation of each option. Cost, availability, awareness, and disagreement among family decision-makers represent some of the more common barriers to service. Once barriers have been encountered, the decision-makers must decide whether to select from among available, affordable

DIAGRAM ONE:

VARIABLES IN STUDY OF

THE DECISION-MAKING PROCESS



- Duration of elder need for care
- Duration of care-giver involvement
- Chronicity
- Precipitating event(s)

- Alternatives identified
- Alternatives investigated
- Advantages and disadvantages of each alternative for client and family explored

- Cost
- Availability
- Familiarity
- Family dymanics

- Specificity of request:
- To find a specific service;
- To achieve a specific goal;
- To solve a specific problem

- Alternatives Identified
- Alternatives investigated
- Advantages and disadvantages of each alternative for client and family explored

- Alternative selected vs. alternatives considered
- Alternative selected vs. Ideal solution

THE IDEAL SOLUTION

THE IDEAL SOLUTION

and viable options, to continue on without altering arrangements already made for care of their aged relative, or to seek assistance from a social service agent.

For those who elect to obtain professional guidance, it is possible that previously unidentified alternatives may surface and the rating process of weighing advantages and disadvantages begins again. And, as was the case before, these new comparisons are made in light of previously identified preferences for some ideal solution. In discussing their situation with the professional to whom they turn for assistance, however, it is possible that the character of the ideal solution may be altered, in part because unknown options become known and in part because the professional may highlight factors for the family which cause them to alter their perception of the ideal.

CJE'S STUDY OF DECISION-MAKING

It was the desire to assure that Council for Jewish Elderly provide services of greatest interest and benefit to its clients (i.e. as close to the ideal as possible) that led the Agency to conduct the research reported on in the present paper. The original plan for and design of CJE's service continuum had been completed over ten years earlier and the Agency sought to analyze the extent to which its original plan, as modified over time, remained responsive to the changing needs of an increasingly frail elderly service population.

Interviews were held with 36 family caregivers who contacted CJE between September and November of 1983 for planning assistance in selecting alternatives to permanent institutionalization of their frail elderly relatives. A total of 45 families were initially contacted (for a response rate of 80 percent). A questionnaire was designed which followed the

conceptual model of decision-making described above. (Available upon request.) Structured, in-person interviews were conducted an average of two and one-half months after the date on which a consultation between the primary family caregiver and one of the Agency's social workers was held. In this way it was possible to analyze retrospectively the full decision-making process, including the eventual choice of a service alternative as well as to analyze the impact of the Agency's consultation services. The questionnaire itself is constructed primarily of open-ended items, particularly in those sections pertaining to alternatives being investigated. Table 1 presents some characteristics of the study's sample.

A. Findings on Service Preferences

The central findings of the research are located in Table 2 which lists the six alternatives most frequently considered by families in our sample and their availability through CJE. In examining the availability of services through the Agency, programs were categorized as either provided, not provided, or access limited. The latter grouping represents services provided by the Agency but which have waiting lists which limit immediate access to care. As indicated, two of the three most frequently considered services are ones not currently provided by CJE -- companions and some form of supportive congregate housing.[2] It appears from this finding that CJE is beginning to

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[2]CJE does offer one type of "supported" housing called Group Living. However, Group living, as practiced at CJE, was not the service respondents in our survey had in mind when they indicated having thought about "congregate housing". The key differences between the two housing options pertains to the issues of privacy and of the level of independence of the older person. Group Living presumes a higher level of independence than is required in congregate living (and that characterized this sample). In addition, congregate living, as envisioned by these families, would provide private, individual apartments. Group Living is closer to a shared living notion with residents having private

(Footnote Continued)

TABLE ONE: SAMPLE CHARACTERISTICS

A. CAREGIVERS

Age

Less than 30	1	2.9
30-39	5	14.5
40-49	8	23.2
50-59	10	29.0
60-69	8	23.2
70-79	1	2.9

Median: 51.9
Mean: 51.1

Relation to Elder

Son	12	33.3
Daughter	10	27.8
Dauger-in-law	5	13.9
Other Relative	4	11.1
Sibling	2	5.6
Grandchild	2	5.6
Son-in-law	1	2 8

Duration of Caregiving

Less than 6 months	5	14.7
6 months to 1 year	2	5.9
1 to 2 years	7	20.6
3 to 4 years	9	26.5
5 or more years	11	32.5

B. ELDERS

Age

60-64	0	
65-74	5	14.5
75-84	11	31.9
85-94	13	44.8
95 and older	2	5.8

Functional Impairment Score (range=0-24)

Lo (0-8)	14	40.6
Medium (9-16)	16	46.4
Hi (17-24)	4	13.8

Median: 10.0
Mean: 9.6

TABLE TWO:

ALTERNATIVES CONSIDERED
DURING DECISION-MAKING PROCESS

ALTERNATIVE	NUMBER	PERCENTAGE[2]	AVAILABILITY THROUGH CJE
Long-Term Care[1]	24	66.7%	Access Limited
Companion	12	33.3	Not Provided
Supported Housing	10	27.8	Not Provided
Counseling[3]	8	22.2	Provided
In-Home Services	6	16.7	Provided
Independent Housing	4	11.1	Access Limited

[1]The high number of respondents considering long-term care reflectes the role of consultations provided by CJE. They are often triggered by families who call the Agency for an application to its nursing home. Intake staff recommend a consultation for many of these families if nursing home placement does not appear absolutely necessary.

[2]Percentages will not sum to 100 due to the inclusion in the table of responses to a whole series of items on alternatives being considered. Each family considered a mean of 2.64 distinct options over the course of the decision-making process.

[3]Couseling was often considered as a means for resolving family conflict over decision-making and, as such, was usually one of several alternatives being considered by the family.

see a frailer population than that for which it had originally designed services.

It must be underlined that these two labels were not necessarily those used by the family caregivers studied. Respondents tended to list the alternatives they were pursuing in descriptive ways, detailing the type of arrangements they had in mind but not placing labels on them. For example, many respondents described their need for supportive housing in terms similar to those used by Mr. L who spoke of "finding a place where she (respondent's mother) could move where she would have her own apartment but where they would help her if she needed it...maybe... have a nurse in case of emergencies and someone to help her wash the floors." The labels companion and congregate housing were selected retrospectively by the researcher as being the service concepts used by professionals which most closely fit the descriptions presented by respondents. (Interestingly, independent assessments of social work staff at the Agency revealed that programs which they labeled to be companion services and congregate living were the two services which the majority of staff members would add first to CJE's service continuum if they were in a position to make such decisions.)

The descriptions of these programs employed by family respondents and those provided by staff members at the Agency were very close with respect to major service components. Specifically, families who considered locating a companion conceived of this alternative as being a solution to one or more of a wide range of problems including: the need for companionship or social stimulation (28.6%); the need for someone to monitor the older person's

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(Footnote Continued)
rooms and baths but sharing living rooms and kitchen facilities with one or more "suite mates".

welfare (57.1%); someone to help take care of personal care tasks (21.4%); and someone to take charge of household chores such as cooking (50%) and housework (64.3%). What each of these families had in common was the need for time intensive service; i.e. someone to live with or be with their older relative 5-7 days a week and at least 8 hours a day. Indeed, 71.4% of respondents saw a companion as being a live-in service.

There was somewhat less variability in the features which families sought from and staff associated with supported congregate living. Of greatest interest were the provision of meals and the availability of congregate social activities. Also very important was the presence of a system for 24 hour response to emergencies. Finally, many of these families also expressed a need for their elderly relative to have his or her own private apartment to fulfill the older person's desire to remain living as independently as possible.

B. Barriers to Service

Additional data of relevance to CJE's planning interests are shown in Table 3, which outlines barriers to successful attainment of preferred alternatives. As indicated, one in four families at some point sought alternatives which they reported to have been unavailable. This highlights the creative potential in studying the problem-solving of these families for it illustrates that families appear to conceive of solutions not provided by the formal service system. In addition, over a third of respondents (35.3%) reported cost as having been a barrier to service while well over half (56.5%) indicated that some option mentioned by the CJE social worker had been unfamiliar to them.

Unfortunately, the size of the sample in this study impeded the ability to analyze effectively the associations, if any, of specific barriers to

TABLE THREE:

BARRIERS TO SERVICE

	Number	Percentage
A. Were any alternatives UNAVAILABLE? (n=36)		
Yes	9	25.0
No	27	75.0
B. Were any alternatives too COSTLY? (n=34)		
Yes	12	35.3
No	22	64.7
C. Were any alternatives suggested by CJE social worker UNFAMILIAR? (n=23)		
Yes	13	56.5
No	10	43.5

specific services or to categorize the "ideal" solutions reported on by the respondents. These would be important components of future research on decision-making. There was some indication that cost was a barrier principally to institutional solutions and to companion care. That cost was a problem in successful use of companions is an important finding for planning purposes in light of the large percentage of families who indicated having considered companion services as one possible solution to their problem.

It was also noteworthy that over half of all caregivers studied indicated that some alternative suggested by the CJE social worker had been unfamiliar to them. Although there was some variability in the nature of unfamiliar alternatives, the two most frequently cited were two of CJE's own more innovative services -- it's Group Living facilities and its Family Support Program.[3] This finding indicated that CJE's efforts to market these programs were not as successful as they could be. It also illustrates an additional use to which research about decision-making can be put by service providers -- namely, evaluation of the effectiveness of marketing techniques used to promote new or innovative programs.

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[3]CJE's Group Living residences are modeled on the shared housing concept and are designed primarily for socially isolated but physically independent elderly persons. Residents occupy their own rooms and have private bathrooms. Rooms are grouped in units which share a common kitchen and living room. All residents attend social programs and at least one meal provided congregately. The Family Support Program provides two distinct services -- Homesharing and Respite. The Homesharing component involves matching of a senior with another person (not necessarily another senior) for the purposes of sharing living quarters. Sharers may or may not provide assistance to one another. The Respite component provides trained aides to stay with elderly persons for specified periods to allow caregivers time for themselves. This could include several scheduled hours a week or an occasional week or weekend to permit vacations.

C. Findings on Family Conflict

A final set of findings obtained in the research pertains to the presence and patterning of family conflict in the decision-making process. As this was not the main goal of the research, the questions of family dynamics in general, and of conflict over alternatives more specially, were addressed in a highly exploratory and non-systematic manner. The findings are based on responses to two questions: 1) whether there was ever an option the respondent had considered which their elderly relative refused to consider; and, 2) whether there was ever an option preferred by the elder family member which the caregiver refused to consider. (It was unclear in some families whether or not these responses actually represent conflict or merely the expression of individual preferences. Research specifically focused on this question would need to be more sensitive to the level of tension in the relationships studied.) In addition, any evidence of conflict between siblings over various options was noted, although no specific questions were included to investigate this type of tension.

This data is presented in Table 4. As can be seen, over one third of respondents (34.6%) said their elderly relative had refused at least one option which the caregiver had considered. In contrast, only 7.7% indicated having refused alternatives suggested by their older relative. This difference is probably accounted for by the fact that few elders actually recommend options for their own care -- an issue not explicitly investigated in this research but which would prove to be a valuable component of future studies on decision-making. It is also noteworthy that almost one caregiver in five (19.2%) responded affirmatively to both questions on refusal by one dyad member of at least one option recommended by the other.

In sum, some level of conflict or disagreement (although these words may prove too strong) between caregiver and elder was present in almost two thirds

TABLE FOUR:

FAMILY DYNAMICS AROUND DECISION-MAKING

	NUMBER	PERCENTAGE
A. Conflict Between Elder and Caregiver (N=26)		
None	10	38.5
Elder refused alternative suggested by caregiver	9	34.6
Caregiver refused alternative suggested by elder	2	7.7
Both elder and caregiver refused an alternative suggested by the other	5	19.2
B. Conflict Mentioned Between other Family Decision-Makers (N=36)		
Yes	6	16.7
No	30	83.3

(61.5%) of cases while 38.5% of families evidenced no disagreements between the two key participants in the decision-making process.

While no direct questions on conflict between others involved in decision-making were included, the responses of caregivers to other items nonetheless revealed the presence of such disagreement in 6 of the 36 families studied (16.7%). In these cases it is the investigator's judgement that the term conflict does accurately reflect the interaction between family members involved to the extent that it was a level of tension salient enough to be noted by the respondent. It is also the impression of the investigator that specific items investigating tension between siblings or other decision-makers (excluding the elder) would reveal a higher rate of conflict than that recorded in the present research with its exploratory approach to this question.

USE OF THE FINDINGS

In response to the findings presented above, CJE has begun a planning effort to analyze further how the needs for companion and supportive congregate living characterizing the sample, and the population it represented, could best be addressed. The 36 respondents surveyed comprised only 11% of the approximately 325 caregivers who annually receive consultations from CJE social workers for assistance in planning for the needs of frail elderly relatives. (An average of 27 consultations are held each month with such families.) As such, the finding that 33% of families studied had considered locating a companion to care for their elderly relative implies interest in this service among at least 108 (324 X .33) such families each year while the 27.8% of studied families who considered congregate housing represent a potential annual demand for this option among at least 90 families. (Interestingly, a companion was also the most frequently requested

service among individuals who called the Agency requesting a service CJE does not provide. These families were referred to other sources.)

As an immediate follow-up to this research, the Agency is currently undertaking surveys of all providers in the Chicago area who offer companions or supportive housing for the elderly. These surveys are focusing on programmatic features such as cost, eligibility, programming, staffing and demand and they will help CJE to ascertain how readily available each service is to the Agency's client population. Once completed, these studies will help guide Agency management in deciding whether to actually design and offer programs to meet these needs as part of CJE's service continuum or to develop directories which will help clients and their families more effectively access programs in each area which already provide these services in our community.

ANALYSIS OF DECISION-MAKING AS A TOOL FOR PLANNERS AND PROVIDERS

From this discussion, it is apparent that research analyzing the decision-making process engaged in by families with frail elderly members can provide data to assist service planners and providers in improving the care they offer. Not only would this type of research help to highlight the criteria which families use to compare alternatives (data not yet analyzed for the present study), findings from such research would also illuminate gaps in the continuum of services available in a community and barriers to attainment of preferred alternatives. Armed with this information, gerontological practitioners would be better prepared to design services in accordance with the preferences and needs of recipients, to develop new programs needed in an area and to organize and market programs so that they are as easy to obtain as possible.

Most significantly perhaps, research on decision-making which acknowledges the importance of the ideal solution as the benchmark for rating

options for care can serve as a powerful tool for creative service design. The creative potential of such research derives primarily from the fact that it would uncover service preferences from the relatively "unadultered" point of view of families -- both in terms of types of service and the formats through which they are delivered. Definitions of the service continuum among families are likely to be less constrained than those of service professionals who are trained to think of service alternatives in terms of labels already defined and categorized by the professional community. In addition, families with frail elders are often forced to be innovative in seeking solutions to their problems. The insightful analyst of decision-making may be able to find in the responses of family members to questions about preferred, ideal solutions, new ideas for new programs or for new ways of delivering existing services.

The potential of this model as a device for research on clinical issues involving family interaction is also significant. As our data indicates, there is a need to examine the dynamics with which families play out the decision-making process. Long-standing family relationships represent the context within which decisions are made. The model presented in this paper, which takes account of the specific individuals involved in decision-making and their relation to one another, provides a framework from which more intensive investigation could be conducted into quality of relationships as a significant variable in explaining selection of services and the effectiveness of solutions chosen by families.

As a final thought, future research on decision-making should take more explicit account of the preferences and reactions of the elderly person him or herself. Our research incorporated this information only indirectly through the caregiver's perceptions of his/her older relative's feelings and

reactions. Yet, it is an empirical question whether or not families accurately portray their older member's characteristics and attitudes. What literature there is on this question appears to indicate a significant level of incongruity between the perceptions of elderly persons and those of their family members. What is more, little, if any, research has been done to investigate more directly the role of the older person in the decision-making process and patterns of influence across participants as options are raised, evaluated and decided upon.